

METHODS

This study used the survey method, with written surveys and telephone interviews, to profile federal and state caregiver support programs in the 50 states and the District of Columbia. A national Advisory Committee of selected experts in the field and stakeholders guided our efforts. We obtained supplemental information from public documents, public agency and research databases, state websites and a literature review. We collected programmatic data for fiscal year 2003 and collected or obtained fiscal and legislative data for fiscal years 2001-2003.

For purposes of the study, the term *family caregiver* includes care provided by relatives, friends or neighbors to persons 60 years or older or adults aged 18-59 with physical and/or adult-onset cognitive disabilities (e.g., Huntington's disease, traumatic brain injury). The persons giving care could be primary or secondary caregivers, provide full or part-time help, and live with or separately from the person receiving care.

To be included in the 50-state study, a program had to be administered by the state and provide support services to family caregivers under: (1) the Older Americans Act's National Family Caregiver Support Program (NFCSP); (2) the Aged/Disabled Medicaid home and community-based services (HCBS) waivers; or (3) state general funds. State-funded programs could be caregiver-specific or have a family caregiver component (e.g., respite care) as part of a home and community-based program aimed at care receivers.

State general fund programs with a "caregiver-specific" focus had these characteristics:

- primarily state funded and administered according to state rules
- provide one or more services (e.g., respite care, family counseling) explicitly to families or friends who care for older people or younger adults with disabilities in need of long-term care.

State-funded HCBS programs with a family caregiver component had these characteristics:

- primarily state funded and administered according to state rules
- target older people or younger adults with disabilities with long-term care needs, *and*
- provide one or more services (e.g., respite care, family counseling) to support family caregivers of the eligible population.

We did not attempt to detail all the publicly funded programs that states administer through which family caregivers may receive some support. Within the array of caregiver support services across the lifespan, we focused on programs for caregivers of the elderly and younger adults with physical and/or adult-onset cognitive disabilities. Consequently, this study did not look at some programs known to be important to family caregivers and people with disabilities, but beyond the study's scope. We did not:

- survey programs serving the target populations of family caregivers of persons with developmental disabilities or grandparents raising grandchildren, or

- ♦ examine programs in states funded by the federal Alzheimer’s Disease Demonstration Grants to States that were considered “stand alone” rather than integrated into a larger caregiver support program.

Identification of Programs and State Contacts

We identified programs and state contacts to include in the study using the following process:

- ♦ based on a literature review, examination of state agency websites and discussions with the project’s Advisory Committee, created an initial list of state programs within the 50 states and the District of Columbia (January-March 2003).
- ♦ compiled a list of key state contacts with knowledge and insights about their state’s program operations and practice, and an understanding of family caregiving issues (January–March 2003).
- ♦ made calls to agency officials responsible for administering the NFCSP, Aged/Disabled Medicaid waivers and state-funded programs to inform them of the study, seek their participation, obtain their contact information and query the existence of any additional state-funded programs that met the study inclusion criteria (April–July 2003).

In all, we identified 154 programs in 71 state agencies in the 50 states and the District of Columbia, an average of three programs per state. We classified each program based on its major source of funding and provisionally assigned it a code:

- ♦ NFCSP (FC)
- ♦ Aged/Disabled Medicaid waivers (MC)
- ♦ state-funded programs with either a caregiver-specific focus, or HCBS programs with a caregiver component (SC).

Several state programs were reclassified later, based on survey responses.

Survey Development

The study’s national Advisory Committee and previous state studies conducted by Family Caregiver Alliance’s National Center on Caregiving (NCC) guided survey development. We chose a three-part approach because of the range of information to be collected and the national scope of the study. FCA’s NCC staff fielded the first two parts of the survey, focusing on programmatic information. Parts 1 and 2 of the 50-state survey were pre-tested with state officials in Alabama and Hawaii. For the third part, FCA’s NCC subcontracted with the National Conference of State Legislatures (NCSL). Part 3 was pretested in New Jersey and Pennsylvania.

- ♦ **Part 1** was a written survey, developed so it could be completed in printed form or electronically, then returned by mail, fax or electronically. We mailed the written survey and cover letter to program officials and also sent them the same material via email with hyperlink access to the Web-based survey instrument. Respondents were asked to complete the survey for each identified program that met the study inclusion criteria. The survey included 30 questions: 29 fixed-choice and one open-ended. The questions addressed program background, program eligibility/assessment process, program administration, services, consumer direction, systems development and other issues. (See Appendix A for a copy of the survey instrument).

- **Part 2** was a semi-structured telephone interview with state respondents, conducted after receipt of their Part 1 written surveys. The Part 2 interview guide included 17 questions: three fixed-choice and 14 open-ended. Our aim in the Part 2 interview was to allow respondents as much freedom as possible in their responses. The interview guide had two sections, the first (8 questions) asked specifically about the program; the second (9 questions) gathered impressions about family caregivers within the state, and about the state's system of HCBS generally. Within the first section, two questions applied only to NFCSP respondents. (See Appendix B for a copy of the interview guide).
- **Part 3** consisted of a fiscal and legislative analysis for the 50 states and the District of Columbia to identify and analyze new and expanded policies, programs and appropriations since the NFCSP's passage in 2000. FCA's NCC selected the NCSL to collect and analyze these data because of NCSL's relationships with the states and familiarity with their data. The NCSL developed the Part 3 instrument in consultation with project staff. It included eight questions addressing caseloads; federal, state, local, private, in-kind and other funding levels; funds used to meet the federally mandated match requirements under the NFCSP; state legislation related to family caregiving; and anticipated funding in future years for family caregiver programs. (See Appendix C for the Part 3 instrument).

Data Collection

We collected data using the following steps:

- sent written survey (Part 1) and cover letter to each identified program to obtain background information on the program and services and identify emerging issues; and assisted, by telephone or e-mail, respondents who reported difficulties with the Web-based format to complete survey on-line (July 2003)
- made up to two follow-up contacts with states by mail, e-mail and telephone to encourage participation (August-October 2003)
- entered Part 1 data received via paper into the Web-based application (October-December 2003)
- sent all Part 1 respondents the Part 2 interview guide (September-October 2003)
- conducted semi-structured telephone interviews (Part 2) to explore more fully the program's successes and challenges, and the relationship to other HCBS programs in the state (September-December 2003)
- provided NCSL with list of Part 1 program contacts (September 2003)
- fielded the fiscal and legislative survey (Part 3) by e-mail and postal mail (October-December 2003, by NCSL)
- sent second copy of Part 3 survey to non-responders (January-February 2004, by NCSL)
- developed codebook and cleaned data (February-April 2004)
- made follow-up calls to state respondents, when necessary, to clarify data or responses for all three parts of the data collection (April-June 2004)
- provided each respondent with a draft of their state's profile to verify the accuracy of the data included in this report (August 2004).

Part 1: Written Survey Response

Of the 154 identified state programs, 150 responded to the written survey in all 50 states and the District of Columbia, representing a 97% response rate overall (See Appendix D). We received responses from 69 state agencies and the District of Columbia, including all 51 administrators of the NFCSP (100% response); 49 Aged/Disabled Medicaid waiver programs (94% response); and 50 state-funded programs (98% response). Over half (57%) of the respondents used the electronic format.

Part 2: Follow-Up Telephone Interview Response

The telephone interviews lasted, on average, 34 minutes. When a respondent was responsible for more than one state program meeting the study criteria, one interview covered all qualifying programs. In some telephone interviews, multiple respondents representing a single program participated.

Of the 150 respondents to the Part 1 survey, 148 (99%) participated in the Part 2 follow-up telephone interview. This response included all 51 administrators of the NFCSP (100%); 48 of the 49 responding waiver programs (98%); and 49 of the 50 state-funded programs (98%).

Part 3: Fiscal and Legislative Trend Analysis Response

NCSL decided to exclude Aged/Disabled Medicaid waiver programs from the Part 3 survey. While Medicaid HCBS waivers are important funding sources for older people, persons with disabilities and their family caregivers, states deliver and pay for services based on the eligibility of the client. The federal government does not require states to track whether a waiver client is also served by a family caregiver. Given the size and scope of many of the HCBS waivers, NCSL determined that asking state officials to separate waiver clients according to the availability of a family caregiver would be very challenging for states and would likely result in inconsistent or incomplete data.

In many cases, state program administrators for the NFCSP forwarded the surveys to fiscal counterparts within their agencies. NCSL researchers conducted follow-up telephone interviews when clarification was needed. To augment survey data, NCSL also used its Health Policy Legislative Tracking Service, the National Association of State Units on Aging's "Promoting Systemic Development of State Family Caregiver Support Programs: State Profiles" from 2002, as well as various online state resource documents.

Program administrators in 43 states and the District of Columbia responded to the Part 3 survey. Responses were received from 43⁶ NFCSP program administrators (84%), and administrators also completed Part 3 surveys for an additional 16 state-funded family caregiver programs (32%).

Data Analysis

We used SPSS for Windows, version 11.0, to analyze the data. Part 1 and Part 2 data were analyzed by the total sample and separately by the three program types (i.e., NFCSP, Medicaid waivers and state general fund programs). We used descriptive statistics, including frequency distributions and cross-tabulations of selected questions, to characterize closed-ended questions. For selected questions that addressed state (rather than pro-

⁶ The 7 states that did not respond to the Part 3 survey were Alaska, Missouri, Ohio, Rhode Island, South Carolina, South Dakota and Wisconsin.

gram) issues, we examined the responses from each of the respondents within a state for congruence. Congruence is defined as the level of agreement among the state respondents within a state in their perceptions or assessment of certain state-level questions in this study. For those questions in which respondents within a state disagreed, we report a “lack of agreement” on the state profile. Any other reported state-level finding indicates all respondents within the state gave the same response.

The project team developed a set of codes to analyze questions with open-ended responses. All questions with an “other” response were coded so that the “other” category included less than 15 percent of all responses for that question. These data were then re-entered into the Web-based application prior to data analysis by SPSS.

For the Part 2 telephone interviews, the project team developed an initial codebook by question based on past surveys conducted by FCA. A qualitative, grounded theory (Glaser & Strauss, 1967) approach was used throughout analysis. The 148 interviews were divided into groups of 10 interviews, and coded two times daily in two-hour periods for nine weeks. Coding teams consisted of two project staff, who each coded the same interview simultaneously, then had a short discussion of the interview and coding scheme to ensure coder reliability.

To determine if any additional codes were necessary, 20 surveys were initially selected at random and analyzed. During this process, we clarified, expanded or narrowed the codes. For data verification, we reanalyzed the first 30 interviews to insure that the data and codes reflected any changes in the codebook. Upon completion of coding, we chose 15 surveys at random and analyzed them by question to ensure no themes were missed. We then calculated frequencies by program type and for the entire sample. We also incorporated data taken from other sources (e.g., legislative and bill information from the NCSL Health Policy Tracking Service) into the database used for the Part 1 and Part 2 data analyses.

For Part 3, NCSL analyzed data using Microsoft Excel. Certain Part 3 data, specifically NFCSP expenditures and NFCSP caseloads, have not been analyzed and are not included in this report. We excluded caseload data from the analysis because of the wide variance of state data reported and the lack of comparable data. For example, some states reported caseloads using a duplicated count, others an unduplicated count. We excluded the NFCSP fiscal data collected based on variance in state fiscal years, carryover of funds from one year to the next, and different reporting and accounting systems.

Fiscal information used in this report is based on data obtained from the following sources:

- ♦ for all years cited, we obtained federal allocations to the states for the NFCSP from the U.S. Administration on Aging
- ♦ we obtained expenditures for state-funded programs from either NCSL’s Part 3 survey or from the state program respondent during the data verification process, where available
- ♦ for fiscal years 2001 and 2002, we obtained Medicaid waiver data from CMS Form 372 for respite participants and expenditures, and total participants and expenditures. For fiscal year 2003, we obtained waiver data from CMS 64 quarterly reports of total expenditures for Aged/Disabled waivers. (For full citations, please see page 264.)